



End of Life Care September 2003

1: Acta Anaesthesiol Scand. 2003 May;47(5):499-500.

Comment on:

Acta Anaesthesiol Scand. 2003 May;47(5):501-7.

End-of-life care in intensive care units save lives that can be saved, offer the dying a peaceful and dignified death.

Klepstad P, Gisvold SE.

Publication Types:

Comment

Editorial

PMID: 12699504 [PubMed - indexed for MEDLINE]

2: Am J Med. 2003 Jul;115(1):47-53.

Older Asian Americans and Pacific Islanders dying of cancer use hospice less frequently than older white patients.

Ngo-Metzger Q, McCarthy EP, Burns RB, Davis RB, Li FP, Phillips RS.

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PURPOSE: Cancer is the leading cause of death among Asian Americans, yet little is known about their use of hospice care. We examined hospice use by Asian patients compared with white patients, and assessed whether utilization differs among those born in the United States or abroad. **METHODS:** We studied Asian and white Medicare beneficiaries registered in the Surveillance, Epidemiology, and End Results (SEER) Program who died of primary lung, colorectal, prostate, breast, gastric, or liver cancer between 1988 and 1998. We used logistic regression to determine the effects of race/ethnicity and birthplace on hospice use, adjusting for demographic characteristics, managed care insurance, year of diagnosis, tumor stage at diagnosis, and tumor registry. **RESULTS:** Of the 184,081 patients, 5% (n = 8614) were Asian Americans, of whom 45% (n = 3847) were foreign born. Compared with whites, Asian Americans were more likely to be male,

married, and enrolled in managed care. Compared with U.S.-born Asian Americans, foreign-born Asian Americans were more likely to reside in low-income areas. After adjustment, patients who were Asian American (odds ratio [OR] = 0.67; 95% confidence interval [CI]: 0.62 to 0.73) and born abroad (OR = 0.90; 95% CI: 0.86 to 0.94) were less likely to use hospice care than were white patients. These results were consistent across the six cancer diagnoses that were examined. CONCLUSION: Older Asian Americans dying of cancer, especially those who are born abroad, are less likely than white patients to use hospice care at the end of life. Additional research is needed to understand the reasons for these differences and to eliminate potential barriers to hospice care.

PMID: 12867234 [PubMed - indexed for MEDLINE]

3: Am J Nurs. 2003 Aug;103(8):13; author reply 13.

Comment on:

Am J Nurs. 2003 May;103(5):52-60; quiz 61.

End-of-life care.

Masson V.

Publication Types:

Comment

Letter

PMID: 12920707 [PubMed - indexed for MEDLINE]

4: Ann Emerg Med. 2003 Aug;42(2):256-60.

Public education regarding resuscitation: effects of a multimedia intervention.

Marco CA, Larkin GL.

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STUDY OBJECTIVE: Previous studies have demonstrated inaccuracies in knowledge and perceptions regarding cardiopulmonary resuscitation (CPR) among the general public. This study was undertaken to determine the effect of a multimedia educational intervention on knowledge base and resuscitation preferences among the lay public. METHODS: In this prospective interventional study with preintervention and postintervention measurements, a validated multisite survey was administered to 310 volunteer lay participants in community-based settings during 2001 and 2002. The survey was piloted and validated (percentage of agreement index 98.6%; 95% confidence interval [CI] 0.9810 to 0.9900). An original 8-minute multimedia educational video was written and produced by physicians to provide educational information about cardiac resuscitation to the lay public. RESULTS: Among 310 participants, the mean age was 40 years (range 17 to 92 years), 67% were female, and 57% reported household incomes of more than 30,000 US dollars. Participants' median estimates of predicted postcardiac

arrest survival rate before and after the educational intervention were 50% and 16%, respectively (median change 30%; 95% CI 25% to 35%). Median estimated durations of resuscitative efforts in the emergency department before and after the educational intervention were 30 minutes and 19 minutes, respectively (median change 10 minutes; 95% CI 5 to 15 minutes). For a series of hypothetical scenarios, significantly more participants indicated that they would refuse resuscitative efforts in scenarios involving terminally ill patients after the educational intervention. CONCLUSION: Inaccurate perceptions regarding cardiac resuscitation and postarrest survival exist among the lay public. A novel educational intervention demonstrated effective improvements in knowledge base regarding resuscitation, resulting in significant effects on resuscitation preferences among the lay public. Improved public education regarding resuscitation is needed to improve knowledge regarding CPR among the lay public.

PMID: 12883514 [PubMed - indexed for MEDLINE]

5: Arch Intern Med. 2003 Jul 28;163(14):1645-9.

"Inappropriate" treatment near the end of life: conflict between religious convictions and clinical judgment.

Brett AS, Jersild P.

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Not infrequently, Christian patients and families provide religious justifications for an insistence on aggressive medical care near the end of life. Four commonly invoked reasons are (1). hope for a miracle, (2). refusal to give up on the God of faith, (3). a conviction that every moment of life is a gift from God and is worth preserving at any cost, and (4). a belief that suffering can have redemptive value. For each of these 4 reasons, however, there are alternative Christian interpretations that point in the direction of limiting medical intervention under certain circumstances. When clinicians believe that an intervention is medically inappropriate or inhumane, they are not necessarily obligated to provide it simply because it is demanded on religious grounds. Instead, clinicians-preferably assisted by chaplains or clergy-should discuss alternative religious interpretations with the patient or family, and should attempt to reach a consensus on the appropriate limits to life-sustaining treatment.

PMID: 12885678 [PubMed - indexed for MEDLINE]

6: BMJ. 2003 Aug 30;327(7413):465.

"Terminal sedation" different from euthanasia, Dutch ministers agree.

Sheldon T.

Publication Types:
News

PMID: 12946953 [PubMed - indexed for MEDLINE]

7: BMJ. 2003 Jul 26;327(7408):202-3.

National survey of medical decisions at end of life made by New Zealand general practitioners.

Mitchell K, Owens RG.

Department of Psychology, University of Auckland, Private Bag 92019, Auckland, New Zealand. k.mitchell@auckland.ac.nz

PMID: 12881263 [PubMed - indexed for MEDLINE]

8: BMJ. 2003 Jul 26;327(7408):201-2.

Twenty five years of requests for euthanasia and physician assisted suicide in Dutch general practice: trend analysis.

Marquet RL, Bartelds A, Visser GJ, Spreeuwenberg P, Peters L.

Netherlands Institute for Health Services Research (NIVEL), Utrecht, Netherlands. r.marquet@nivel.nl

PMID: 12881262 [PubMed - indexed for MEDLINE]

9: BMJ. 2003 Jul 26;327(7408):192-4.

A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas.

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OBJECTIVE: To identify the palliative care needs of terminally ill people in Uganda. DESIGN: Descriptive cross sectional study. SETTING: Home care programmes in and around Kampala that look after terminally ill people in their homes. PARTICIPANTS: 173 terminally ill patients registered with the home care programmes. RESULTS: Most of the participants had either HIV/AIDS or cancer or both; 145 were aged under 50 years, and 107 were women. Three main needs were identified: the control or relief of pain and other symptoms; counselling; and financial assistance for basic needs such as food, shelter, and school fees for their children. The preferred site of care was the home, though all these people lived in urban areas with access to healthcare services within 5 km of their homes. CONCLUSION: A "good death" in a developing country occurs when the dying

person is being cared for at home, is free from pain or other distressing symptoms, feels no stigma, is at peace, and has their basic needs met without feeling dependent on others.

PMID: 12881259 [PubMed - indexed for MEDLINE]

10: BMJ. 2003 Jul 26;327(7408):185.

Doctors' emotional reactions to recent death of a patient: cross sectional study of hospital doctors.

Redinbaugh EM, Sullivan AM, Block SD, Gadmer NM, Lakoma M, Mitchell AM, Seltzer D, Wolford J, Arnold RM.

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OBJECTIVES: To describe doctors' emotional reactions to the recent death of an "average" patient and to explore the effects of level of training on doctors' reactions. **DESIGN:** Cross sectional study using quantitative and qualitative data. **SETTING:** Two academic teaching hospitals in the United States. **PARTICIPANTS:** 188 doctors (attending physicians (equivalent to UK consultants), residents (equivalent to UK senior house officers), and interns (equivalent to UK junior house officers)) who cared for 68 patients who died in the hospital. **MAIN OUTCOME MEASURES:** Doctors' experiences in providing care, their emotional reactions to the patient's death, and their use of coping and social resources to manage their emotions. **RESULTS:** Most doctors (139/188, 74%) reported satisfying experiences in caring for a dying patient. Doctors reported moderate levels of emotional impact (mean 4.7 (SD 2.4) on a 0-10 scale) from the death. Women and those doctors who had cared for the patient for a longer time experienced stronger emotional reactions. Level of training was not related to emotional reactions, but interns reported needing significantly more emotional support than attending physicians. Although most junior doctors discussed the patient's death with an attending physician, less than a quarter of interns and residents found senior teaching staff (attending physicians) to be the most helpful source of support. **CONCLUSIONS:** Doctors who spend a longer time caring for their patients get to know them better but this also makes them more vulnerable to feelings of loss when these patients die. Medical teams may benefit from debriefing within the department to give junior doctors an opportunity to share emotional responses and reflect on the patient's death.

Publication Types:
Multicenter Study

PMID: 12881257 [PubMed - indexed for MEDLINE]

11: BMJ. 2003 Jul 26;327(7408):180.

Freedom from unpleasant symptoms is essential for a good death.

Clark J.

Publication Types:
News

PMID: 12881238 [PubMed - indexed for MEDLINE]

12: BMJ. 2003 Jul 26;327(7408):174-5.

Patient centred death.

Clark J.

Publication Types:
Editorial

PMID: 12881232 [PubMed - indexed for MEDLINE]

13: BMJ. 2003 Jul 26;327(7408):173-4.

"The best places to die".

Singer PA, Wolfson M.

Publication Types:
Editorial

PMID: 12881231 [PubMed - indexed for MEDLINE]

14: BMJ. 2003 Jul 26;327(7408):198.

Novel consent process for research in dying patients unable to give consent.

Rees E, Hardy J.

Department of Palliative Medicine, Royal Marsden Hospital, Sutton, Surrey SM2 5PT.

OBJECTIVES: To develop a process of advance consent to enable research to be undertaken in patients in the terminal phase. DESIGN: Feasibility study of an advance consent process to support a randomised controlled trial of two antimuscarinic drugs (hyoscine hydrobromide and glycopyrronium bromide) in the management of noisy respirations associated with retained secretions ("death rattle"). SETTING: Palliative care wards in a major cancer centre. PARTICIPANTS: Patients admitted to a palliative care ward who may develop "death rattle" and thus be eligible for randomisation. MAIN OUTCOME MEASURES: Patient accrual; acceptability of the consent process. RESULTS: Of the 107 patients approached, 58 patients gave advance consent to participate in the study. Of these, 15 patients developed death rattle and were randomised to receive either hyoscine or glycopyrronium; 16 patients died elsewhere; 15 patients died on the

palliative care wards but were not randomised; 12 patients are still alive.
CONCLUSIONS: Initial assessment suggests that this is a workable consent process allowing research to be undertaken in patients who are unable to give consent at the time of randomisation. Patient accrual rates to date are lower than needed to recruit adequate numbers in the time allotted to answer the research question.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 12881261 [PubMed - indexed for MEDLINE]

15: BMJ. 2003 Jul 26;327(7408):204-6; discussion 206-7.

Planning for a good death: responding to unexpected events.

Saunders Y, Ross JR, Riley J.

Department of Palliative Medicine, Royal Marsden Hospital, London SW3 6JJ.
yolandes@doctors.org.uk

PMID: 12881264 [PubMed - indexed for MEDLINE]

16: BMJ. 2003 Jul 26;327(7408):207-8.

Erratum in:

BMJ. 2003 Aug 23;327(7412):422.

A healthy view of dying.

Neuberger J.

King's Fund, London W1G 0AN. j.neuberger@kingsfund.org.uk

Publication Types:

Review

Review, Tutorial

PMID: 12881266 [PubMed - indexed for MEDLINE]

17: BMJ. 2003 Jul 26;327(7408):209-13.

Quality care at the end of life in Africa.

Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Mudanga B, Ngoma T, Solomon B.

Programme on Cancer Control, World Health Organization, Avenue Appia 20, CH-1211 Geneva 27, Switzerland. sepulvedac@who.int

Publication Types:
Review
Review, Tutorial

PMID: 12881267 [PubMed - indexed for MEDLINE]

18: BMJ. 2003 Jul 26;327(7408):213-5.

Patients' voices are needed in debates on euthanasia.

Mak YY, Elwyn G, Finlay IG.

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Publication Types:
Review
Review, Tutorial

PMID: 12881268 [PubMed - indexed for MEDLINE]

19: BMJ. 2003 Jul 26;327(7408):222.

Comment on:
BMJ. 2003 Feb 15;326(7385):368.

In search of a good death: Health professionals' beliefs may undermine effective pain relief for dying patients.

Cuttini M, Casotto V, Saracci R, Orzalesi M.

Publication Types:
Comment
Letter

PMID: 12881274 [PubMed - indexed for MEDLINE]

20: BMJ. 2003 Jul 26;327(7408):222.

Comment on:
BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: A good death is an oxymoron without consideration of mental health.

Prigerson HG, Jacobs SC, Bradley EH, Kasl SV.

Publication Types:
Comment
Letter

PMID: 12881276 [PubMed - indexed for MEDLINE]

21: BMJ. 2003 Jul 26;327(7408):223-4.

Comment on:
BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: Good death is social construction.

Curtis MJ.

Publication Types:
Comment
Letter

PMID: 12881278 [PubMed - indexed for MEDLINE]

22: BMJ. 2003 Jul 26;327(7408):223.

Comment on:
BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: Palliative care is also remit of intensivists.

Rashid A, Ferguson M.

Publication Types:
Comment
Letter

PMID: 12881279 [PubMed - indexed for MEDLINE]

23: BMJ. 2003 Jul 26;327(7408):224.

Comment on:
BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: Spiritual care is important for a good death.

Clark BA.

Publication Types:
Comment
Letter

PMID: 12881282 [PubMed - indexed for MEDLINE]

24: BMJ. 2003 Jul 26;327(7408):221.

In search of a good death: Doctors need to know when and how to say die.

Workman SR.

Publication Types:
Letter

PMID: 12881272 [PubMed - indexed for MEDLINE]

25: BMJ. 2003 Jul 26;327(7408):189.

Effects of euthanasia on the bereaved family and friends: a cross sectional study.

Swarte NB, van der Lee ML, van der Bom JG, van den Bout J, Heintz AP.

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OBJECTIVE: To assess how euthanasia in terminally ill cancer patients affects the grief response of bereaved family and friends. **DESIGN:** Cross sectional study. **SETTING:** Tertiary referral centre for oncology patients in Utrecht, the Netherlands. **PARTICIPANTS:** 189 bereaved family members and close friends of terminally ill cancer patients who died by euthanasia and 316 bereaved family members and close friends of comparable cancer patients who died a natural death between 1992 and 1999. **MAIN OUTCOME MEASURES:** Symptoms of traumatic grief assessed by the inventory of traumatic grief, current feelings of grief assessed by the Texas revised inventory of grief, and post-traumatic stress reactions assessed by the impact of event scale. **RESULTS:** The bereaved family and friends of cancer patients who died by euthanasia had less traumatic grief symptoms (adjusted difference -5.29 (95% confidence interval -8.44 to -2.15)), less current feeling of grief (adjusted difference 2.93 (0.85 to 5.01)); and less post-traumatic stress reactions (adjusted difference -2.79 (-5.33 to -0.25)) than the family and friends of patients who died of natural causes. These differences were independent of other risk factors. **CONCLUSIONS:** The bereaved family and friends of cancer patients who died by euthanasia coped better with respect to grief symptoms and post-traumatic stress reactions than the bereaved of comparable cancer patients who died a natural death. These results should not be interpreted as a plea for euthanasia, but as a plea for the same level of care and openness in all patients who are terminally ill.

PMID: 12881258 [PubMed - indexed for MEDLINE]

26: BMJ. 2003 Jul 26;327(7408):226.

Comment on:

BMJ. 2003 Jul 5;327(7405):52; author reply 52-3.

In search of a good death: Do we really know what happens in this country?

Kalbag RM.

Publication Types:

Comment

Letter

PMID: 12881288 [PubMed - indexed for MEDLINE]

27: BMJ. 2003 Jul 26;327(7408):225-6.

In search of a good death: Law needs to be changed to allow terminally ill people choice of a dignified death.

Cook L.

Publication Types:

Letter

PMID: 12881286 [PubMed - indexed for MEDLINE]

28: BMJ. 2003 Jul 26;327(7408):224.

Comment on:

BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: Each encounter with a dying patient is a unique privilege.

Knowles S.

Publication Types:

Comment

Letter

PMID: 12881284 [PubMed - indexed for MEDLINE]

29: BMJ. 2003 Jul 26;327(7408):224.

Comment on:

BMJ. 2003 Jan 4;326(7379):30-4.

In search of a good death: Spiritual care of dying patients needs to be well prepared.

El-Nimr G, Green L, Salib E.

Publication Types:

Comment

Letter

PMID: 12881283 [PubMed - indexed for MEDLINE]

30: CA Cancer J Clin. 2003 Jul-Aug;53(4):202-3.

Medicare managed care patients more likely to use hospice.

[No authors listed]

Publication Types:

News

PMID: 12924772 [PubMed - indexed for MEDLINE]

31: Chest. 2003 Aug;124(2):771-2.

Comment on:

Chest. 2002 Jul;122(1):356-62.

Another view of end-of-life care.

Nakayama CK.

Publication Types:

Comment

Letter

PMID: 12907579 [PubMed - indexed for MEDLINE]

32: Clin Med. 2003 Mar-Apr;3(2):176-8.

Artificial nutrition and hydration: science, ethics and law.

McIlmoyle J, Vernon MJ.

Department of Elderly Medicine, Manchester Royal Infirmary.

Publication Types:

Congresses

PMID: 12737379 [PubMed - indexed for MEDLINE]

33: Clin Med. 2003 Mar-Apr;3(2):149-52.

Comment in:

Clin Med. 2003 Mar-Apr;3(2):97-8.

'If only someone had told me . . .' A review of the care of patients dying in hospital.

Edmonds P, Rogers A.

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Approximately half of all patients who die do so in hospital. Despite the advent of palliative care in the UK, there is evidence that the care that many patients receive in the final phase of their illness in hospital is poor. Building on a study of bereaved relatives' views of the information provided by an inner city hospital trust during an admission in which a patient died, this article explores the factors that may contribute to sub-optimal care for patients dying in hospital. In particular, a lack of open communication, difficulties in accurate prognostication and a lack of planning of end-of-life care can all result in poor care. Strategies to improve care, such as the use of integrated care pathways, advance directives and education initiatives, are discussed.

Publication Types:

Review

Review, Tutorial

PMID: 12737372 [PubMed - indexed for MEDLINE]

34: Clin Med. 2003 Mar-Apr;3(2):142-8.

A pretty pass: when is there a right to die?

Hale B.

Court of Appeal, Royal Courts of Justice, London.

This paper discusses the present extent and limits of a persons right to choose when and how to die, in the light of the contrasting decisions in the cases of Mrs Pretty (who was not allowed the choice) and Ms B (who was), and of the European Convention of Human Rights. It also discusses whether the Convention might eventually develop a right to self determination which would include such a right.

PMID: 12737371 [PubMed - indexed for MEDLINE]

35: Clin Med. 2003 Mar-Apr;3(2):102-3.

Comment in:

Clin Med. 2003 Mar-Apr;3(2):97-8.

Dying with dignity.

Finlay I.

Publication Types:
Editorial

PMID: 12737361 [PubMed - indexed for MEDLINE]

36: Clin Med. 2003 Mar-Apr;3(2):97-8.

Comment on:
Clin Med. 2003 Mar-Apr;3(2):102-3.
Clin Med. 2003 Mar-Apr;3(2):149-52.

The ceaseless pursuit of triumph over death in life.

Watkins P.

Publication Types:
Comment
Editorial

PMID: 12737359 [PubMed - indexed for MEDLINE]

37: Conn Med. 2003 May;67(5):283-90; discussion 291-2.

Are living wills useful? In search of a new paradigm.

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Living wills are written by patients to direct physicians and loved ones as to the medical care they want in the event of catastrophic illness that is accompanied by inability to communicate their wishes. We outline recent data suggesting that living wills are poorly understood by patients who have them and that the usefulness of these documents in the clinical arena is extremely limited. Potential solutions for current deficiencies in end-of-life care and decision-making are discussed.

Publication Types:
Review
Review, Tutorial

PMID: 12802843 [PubMed - indexed for MEDLINE]

38: Crit Care Med. 2003 Jul;31(7):1895-900.

Comment in:

Crit Care Med. 2003 Jul;31(7):2072-3.

Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients.

Hardart GE, Truog RD.

Department of Anesthesia, Children's Hospital, Boston, MA, USA.

OBJECTIVE: The role of family interests in medical decision making is controversial. Physicians who routinely treat incompetent patients may have preferred strategies for addressing family interests as they are encountered in surrogate medical decision making. We sought to determine how physicians view the role of family interests in surrogate medical decision making. **DESIGN:** Cross-sectional mail survey. **SETTING:** Remote study. **PATIENTS:** Surveyed were neonatologists, pediatric intensivists, and medical intensivists affiliated with American medical schools. **MEASUREMENTS AND MAIN RESULTS:** A total of 327 (55%) of

596 surveys were returned; 35% of respondents were pediatric intensivists, 39% were neonatologists, and 26% were medical intensivists. The majority of respondents believed that family interests should be considered in decisions for incompetent patients, even if those interests are not necessarily important interests of the patient. Less than 10% preferred the traditional model in which the physician-patient relationship is exclusive and family interests are excluded. Medical intensivists, and those who described themselves as more religious, more opposed to healthcare rationing, and more protective of patients, tended to prefer patient-centered surrogate decision-making models. Physicians who treat children, especially neonatologists, were more accepting of family-centered surrogate decision-making models than were physicians who exclusively treat adults. **CONCLUSIONS:** A majority of the academic intensivists in our study believed that family interests should play an important role in medical decision making for incompetent patients. Our findings suggest that the traditional view of the physician-patient relationship may represent an overly simplistic model for medical decision making.

PMID: 12847380 [PubMed - indexed for MEDLINE]

39: Crit Care Med. 2003 Jul;31(7):2072-3.

Comment on:

Crit Care Med. 2003 Jul;31(7):1895-900.

Physicians and family interests.

Nelson JL.

Publication Types:

Comment

Editorial

PMID: 12847406 [PubMed - indexed for MEDLINE]

40: Eur J Cancer Care (Engl). 2003 Sep;12(3):212-4.

End-of-life decision making--have we got it right?

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There are wide-spread misconceptions about palliative care. Various treatments used in palliative care have a potential to shorten, and at times even prolong life. However, such treatments are used with a view to enhance quality of life and/or death. Withholding and withdrawal of life-prolonging treatments are not equivalent to assisting death. It is important that patients who are approaching death are sensitively encouraged to make informed choices about such treatments. At the same time, there is no obligation on part of a health professional to provide a futile treatment. This personal view of two palliative care physicians aims to explore some of the difficulties surrounding end-of-life care.

PMID: 12919299 [PubMed - in process]

41: Eur J Health Law. 2003 Mar;10(1):63-4.

Laws and practices relating to euthanasia and assisted suicide in 34 countries of the Council of Europe and the USA.

Mackellar C.

Publication Types:
News

PMID: 12908208 [PubMed - indexed for MEDLINE]

42: Eur J Oncol Nurs. 2003 Jun;7(2):120-9.

Emotional support for dying patients--the nurses' perspective.

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merja.kuuppelomaki@seamk.fi

This study describes and explains the provision of emotional support to the dying patients from the nurses' viewpoint. The results are part of a questionnaire survey concerned with terminal care on inpatient wards at

community health centres in Finland. The sample consisted of 328 nurses from 32 health centres. The data were collected using a structured questionnaire in which emotional support was measured by multiple-choice items and one open-ended question. The data were analysed using content analysis. Listening, touching, expressing empathy, attending to the patients' wishes, comforting, encouraging and being present were the most common forms of emotional support. The support was mainly provided in connection with basic care. Problems concerning the provision of emotional support were focused on organisational resources, nursing staff, patients and family members. The size of the health centre, further training in the care of terminal patients and reading the literature were associated with the provision of support. In conclusion, nurses feel they need time as well as sufficient skills and competencies so that they can provide emotional support to the extent and in the way that they themselves want to.

PMID: 12849565 [PubMed - indexed for MEDLINE]

43: Fam Med. 2003 Sep;35(8):552-4.

Tuesdays With Morrie: A Humanities Teaching Exercise in Palliative and End-of-life Care.

Ring JM, Reilly JM.

Family Practice Residency Program, White Memorial Medical Center, Los Angeles.

PMID: 12947517 [PubMed - in process]

44: Hastings Cent Rep. 2003 Mar-Apr;33(2):12; discussion 12-3.

Removing the mask.

Fulton GB, Fins JJ.

PMID: 12760113 [PubMed - indexed for MEDLINE]

45: Hawaii Med J. 2003 Jun;62(6):128-9.

End-of-life care curriculum for internal medicine residents at the John A. Burns School of Medicine, University of Hawaii.

Nguyen LV, Williams S, Somogyi-Zalud E.

Division of Geriatric Medicine, John A. Burns School of Medicine, USA.

PMID: 12886728 [PubMed - indexed for MEDLINE]

46: Hosp Health Netw. 2003 Aug;77(8):60-4, 66, 2.

2003 Circle of Life Awards.

Bilchik GS.

These three winning programs are changing palliative and end-of-life care in their communities, stretching the boundaries of conventional thinking, redefining eligibility, seeking out previously underserved populations, and otherwise serving as role models.

PMID: 12947787 [PubMed - indexed for MEDLINE]

47: Hosp Med. 2003 Jul;64(7):425-8.

Cardiopulmonary resuscitation: attitudes and perceptions of junior doctors.

Scott G, Mulgrew E, Smith T.

Elderly Health Unit, Broadgreen Hospital, Liverpool L14 3LB.

Many junior doctors feel cardiac arrests are unsatisfactorily managed and experience high levels of stress during the procedure, often feeling they are inadequately trained for the task. Juniors also regard 'do not resuscitate' orders as decisions for teams, not individuals.

Publication Types:

Review

Review, Tutorial

PMID: 12886854 [PubMed - indexed for MEDLINE]

48: J Adv Nurs. 2003 Jul;43(2):206-15.

Transition experiences of qualified nurses moving into hospice nursing.

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BACKGROUND: Over a short period of time a number of nurses had joined the staff at a hospice. Many of these nurses were palliative care novices, and thus their transition into hospice nursing constituted a move both to a new workplace and a new clinical specialism. **AIM:** The aim of the study was to gain a deeper understanding of the experiences of qualified nurses making the transition into hospice nursing in order to support future nurses in this transition. **METHOD:** A constructivist approach was used; data were collected through semi-structured interviews with four new nurses, three mentors and four team leaders. Data were analysed using a constant comparative method. **FINDINGS:** Five major themes were identified: expectations, personal and professional development, professional

respect, mentorship and support. Nurses came to the hospice with individual expectations, some of which were realized. All identified areas of personal and professional development. Whilst it was acknowledged that new nurses brought transferable skills, there was consensus that they needed to develop palliative care knowledge and skills. Professional respect was demonstrated by the degree of acceptance or questioning of new nurses by established staff. New nurses experienced a variety of emotional responses to hospice nursing. Mentorship enhanced the transition experience and strong support was also gained from each other. CONCLUSIONS: New nurses need individual support during their transition into hospice nursing in response to their own expectations, experiences and learning needs. Mentors need preparation and support in their role in order to maximize their positive influence on transitions.

PMID: 12834379 [PubMed - indexed for MEDLINE]

49: J Am Board Fam Pract. 2003 May-Jun;16(3):265-6.

Comment on:

J Am Board Fam Pract. 2003 May-Jun;16(3):262-4.

Staying connected to hospice patients.

Stephens GG.

Publication Types:

Comment

Editorial

PMID: 12755258 [PubMed - indexed for MEDLINE]

50: J Am Board Fam Pract. 2003 May-Jun;16(3):262-4.

Comment in:

J Am Board Fam Pract. 2003 May-Jun;16(3):265-6.

Medical student reflects on hospice experience.

Baker BL, Joyce JM.

College of Medicine, University of Kentucky, Lexington, USA.

PMID: 12755257 [PubMed - indexed for MEDLINE]

51: J Am Geriatr Soc. 2003 Jul;51(7):961-9.

Life-sustaining treatments: what do physicians want and do they express their wishes to others?

Gallo JJ, Straton JB, Klag MJ, Meoni LA, Sulmasy DP, Wang NY, Ford DE.

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OBJECTIVES: To assess whether older physicians have discussed their preferences for medical care at the end of life with their physicians, whether they have established an advance directive, and what life-sustaining treatment they wish in the event of incapacity to make these decisions for themselves. **DESIGN:** Mailed survey to a cohort of physicians. **SETTING:** Physicians who were medical students at the Johns Hopkins University in graduating classes from 1946 to 1964. **PARTICIPANTS:** Physicians who completed the advance directive questionnaire (mean age 68). **MEASUREMENTS:** Questionnaires were sent out to known surviving physicians of the Precursors Study, an on-going study that began in 1946, asking physicians about their preferences for life-sustaining treatments. **RESULTS:** Of 999 physicians who were sent the survey, 765 (77%) responded. Forty-six percent of the physicians felt that their own doctors were unaware of their treatment preferences or were not sure, and of these respondents, 59% had no intention of discussing their wishes with their doctors within the next year. In contrast, 89% thought their families were probably or definitely aware of their preferences. Sixty-four percent reported that they had established an advance directive. Compared with physicians without advance directives, physicians who established an advance directive were more likely to believe that their doctors (odds ratio (OR) = 3.42, 95% confidence interval (CI) = 2.49-4.69) or family members (OR = 9.58, 95% CI = 5.33-17.23) were aware of their preferences for end-of-life care and were more likely to refuse treatments than those without advance directives. **CONCLUSION:** This survey of physicians calls attention to the gap between preferences for medical care at the end of life and expressing wishes to others through discussion and advance directives, even among physicians.

PMID: 12834516 [PubMed - indexed for MEDLINE]

52: J Am Geriatr Soc. 2003 Jul;51(7):1046-7.

Management of hip fractures in the terminally ill.

Fortier D, Guzman T.

Publication Types:
Letter

PMID: 12834536 [PubMed - indexed for MEDLINE]

53: J Am Med Dir Assoc. 2003 Jul-Aug;4(4):195-9.

Comment in:
J Am Med Dir Assoc. 2003 Jul-Aug;4(4):220-1.

Associations among processes and outcomes of care for Medicare nursing home residents with acute heart failure.

Hutt E, Frederickson E, Ecord M, Kramer AM.

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OBJECTIVE: To characterize Medicare skilled nursing facility (SNF) residents who become acutely ill with heart failure (HF) and assess the association between the outcomes of rehospitalization and mortality, and severity of the acute exacerbation, comorbidity, and processes of care. **DESIGN:** SNF medical record review of Medicare patients who developed an acute exacerbation of heart failure (HF) during the 90 days following nursing home admission. **SETTING:** A total of 58 SNFs in 5 states during 1994 and 1997. **PARTICIPANTS:** Patients with 156 episodes of acute HF among 4693 random Medicare nursing home admissions.

MEASUREMENTS:

Demographic variables, symptoms, signs, comorbidity, nursing home characteristics, nurse staffing ratios, and processes of care were compared between acute HF subjects transferred to hospital and those not transferred; and between subjects who died within 30 days of an acute exacerbation and those who survived. **RESULTS:** After adjusting for age, disease severity, and comorbidity, residents whose change in condition was evaluated during the night shift were more likely to be hospitalized (OR 4.20, 95%CI 1.01-17.50). Residents who were prescribed an angiotensin-converting enzyme inhibitor or who received an order for skilled nursing observation more often than once a shift were 1/3 as likely to die as those who did not (OR 0.303, 95%CI 0.11-0.82), after adjusting for hypotension, delirium, do not resuscitate orders, and prior hospital length of stay. **CONCLUSION:** For residents who develop an acute exacerbation of HF during a SNF stay, there is an association between attributes of nursing home care and the outcomes of rehospitalization and mortality.

PMID: 12837140 [PubMed - indexed for MEDLINE]

54: J Clin Oncol. 2003 Aug 1;21(15):3000-2.

Allowing patients to die: practical, ethical, and religious concerns.

Kahn MJ, Lazarus CJ, Owens DP.

Department of Medicine and Psychiatry, Tulane University School of Medicine, New Orleans, LA 70112, USA. mkahn@tulane.edu.

PMID: 12885824 [PubMed - indexed for MEDLINE]

55: J Gen Intern Med. 2003 Sep;18(9):685-95.

The Status of Medical Education in End-of-life Care.

Sullivan AM, Lakoma MD, Block SD.

Received from the Dana-Farber Cancer Institute (AS, ML, SB) and Brigham and Women's Hospital, Harvard Medical School (AS, SB), Boston, Mass.

OBJECTIVE: To assess the status of medical education in end-of-life care and identify opportunities for improvement. DESIGN: Telephone survey. SETTING: U.S. academic medical centers. PARTICIPANTS: National probability sample of 1,455 students, 296 residents, and 287 faculty (response rates 62%, 56%, and 41%, respectively) affiliated with a random sample of 62 accredited U.S. medical schools. MEASUREMENTS AND MAIN RESULTS: Measurements assessed attitudes, quantity and quality of education, preparation to provide or teach care, and perceived value of care for dying patients. Ninety percent or more of respondents held positive views about physicians' responsibility and ability to help dying patients. However, fewer than 18% of students and residents received formal end-of-life care education, 39% of students reported being unprepared to address patients' fears, and nearly half felt unprepared to manage their feelings about patients' deaths or help bereaved families. More than 40% of residents felt unprepared to teach end-of-life care. More than 40% of respondents reported that dying patients were not considered good teaching cases, and that meeting psychosocial needs of dying patients was not considered a core competency. Forty-nine percent of students had told patients about the existence of a life-threatening illness, but only half received feedback from residents or attendings; nearly all residents had talked with patients about wishes for end-of-life care, and 33% received no feedback. CONCLUSIONS: Students and residents in the United States feel unprepared to provide, and faculty and residents unprepared to teach, many key components of good care for the dying. Current educational practices and institutional culture in U.S. medical schools do not support adequate end-of-life care, and attention to both curricular and cultural change are needed to improve end-of-life care education.

PMID: 12950476 [PubMed - in process]

56: J Pain Symptom Manage. 2003 Jul;26(1):589-90; author reply 590.

Comment on:

J Pain Symptom Manage. 2002 Oct;24(4):398-403.

Re: The fentanyl transdermal patch in the dying phase.

Kirkham SR.

Publication Types:

Comment

Letter

PMID: 12850638 [PubMed - indexed for MEDLINE]

57: J Pain Symptom Manage. 2003 Jul;26(1):684-6.

Anticholinergic agents for the treatment of "death rattle" in patients with myasthenia gravis.

Spiess JL, Scott SD.

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Difficulty clearing upper airway secretions (death rattle) is a frequent problem at the end of life. Treatment often includes the use of anticholinergic drugs. Myasthenia gravis is a disease characterized by muscle weakness and fatigue caused by an immune-mediated deficiency of acetylcholine receptors at the neuromuscular junction, and it is treated with anticholinesterase agents. We report the case of a patient dying of myasthenia gravis who had problems with the "death rattle" and who presented a dilemma as to whether the use of anticholinergics would be helpful or would cause deterioration of her myasthenia. This is accompanied by a review of the relevant literature.

PMID: 12850651 [PubMed - indexed for MEDLINE]

58: J Pastoral Care Counsel. 2003 Summer;57(2):131-41.

Spiritual distress at life's end: finding meaning in the maelstrom.

Kennedy C, Cheston SE.

Spiritual and Bereavement Care Center, Hospice of the Chesapeake, 8424 Veterans Hwy, Millersville, MD 21108, USA.

Recent trends in social research indicate a decline in church attendance and a corresponding increased interest in spirituality. With the aging of the population, attention to end of life care, with its corresponding spiritual concerns and distress, has become a prominent issue. Spiritual distress can be difficult to distinguish from psychological and physical distress and indicates the need for differential diagnostic markers to distinguish between genuine spiritual experience and psychosis related to the physical death process. Further, for hospice patients who are in genuine need of amelioration through pharmacologic suppression, the question of when and how to medicate becomes paramount as the distinction between spiritual process and psychosis becomes less evident. This article is an exploratory attempt to encourage dialogue across interdisciplinary lines and foster participation from alternative therapies representing the spiritual context of the patient. Anecdotal data from hospice professionals representing a variety of disciplines are presented to illustrate and emphasize the need for continued dialogue and research in this important area.

PMID: 12875121 [PubMed - indexed for MEDLINE]

59: JAMA. 2003 Aug 13;290(6):820-2.

Comment on:

JAMA. 2003 Aug 13;290(6):790-7.

Caring for the dying in the intensive care unit: in search of clarity.

Rocker GM, Curtis JR.

Publication Types:

Comment
Editorial

PMID: 12915438 [PubMed - indexed for MEDLINE]

60: JAMA. 2003 Aug 13;290(6):815.

Comment on:

JAMA. 2003 Apr 23-30;289(16):2113-9.

Practical considerations in dialysis withdrawal: "to have that option is a blessing".

Markowitz AJ, Rabow MW.

Publication Types:

Comment

PMID: 12915435 [PubMed - indexed for MEDLINE]

61: JAMA. 2003 Aug 13;290(6):790-7.

Comment in:

JAMA. 2003 Aug 13;290(6):820-2.

End-of-life practices in European intensive care units: the Ethicus Study.

Sprung CL, Cohen SL, Sjobqvist P, Baras M, Bulow HH, Hovilehto S, Ledoux D, Lippert A, Maia P, Phelan D, Schobersberger W, Wennberg E, Woodcock T; Ethicus Study Group.

Department of Anesthesiology and Critical Care Medicine, Hadassah Hebrew University Medical Center, Jerusalem, Israel.

CONTEXT: While the adoption of practice guidelines is standardizing many aspects of patient care, ethical dilemmas are occurring because of forgoing life-sustaining therapies in intensive care and are dealt with in diverse ways between different countries and cultures. OBJECTIVES: To determine the frequency and types of actual end-of-life practices in European intensive care units (ICUs) and to analyze the similarities and differences. DESIGN AND SETTING: A prospective, observational study of European ICUs. PARTICIPANTS: Consecutive patients who died or had any limitation of therapy. INTERVENTION: Prospectively defined end-of-life practices in 37 ICUs in 17 European countries were studied from January 1, 1999, to June 30, 2000. MAIN OUTCOME MEASURES: Comparison and analysis of the frequencies and patterns of end-of-life care by geographic regions and different patients and professionals. RESULTS: Of 31 417 patients admitted to ICUs, 4248 patients (13.5%) died or had a limitation of

life-sustaining therapy. Of these, 3086 patients (72.6%) had limitations of treatments (10% of admissions). Substantial intercountry variability was found in the limitations and the manner of dying: unsuccessful cardiopulmonary resuscitation in 20% (range, 5%-48%), brain death in 8% (range, 0%-15%), withholding therapy in 38% (range, 16%-70%), withdrawing therapy in 33% (range, 5%-69%), and active shortening of the dying process in 2% (range, 0%-19%). Shortening of the dying process was reported in 7 countries. Doses of opioids and benzodiazepines reported for shortening of the dying process were in the same range as those used for symptom relief in previous studies. Limitation of therapy vs continuation of life-sustaining therapy was associated with patient age, acute and chronic diagnoses, number of days in ICU, region, and religion ($P<.001$). CONCLUSION: The limiting of life-sustaining treatment in European ICUs is common and variable. Limitations were associated with patient age, diagnoses, ICU stay, and geographic and religious factors. Although shortening of the dying process is rare, clarity between withdrawing therapies and shortening of the dying process and between therapies intended to relieve pain and suffering and those intended to shorten the dying process may be lacking.

Publication Types:
Multicenter Study

PMID: 12915432 [PubMed - indexed for MEDLINE]

62: Lancet. 2003 Aug 2;362(9381):395-9.

Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001.

Onwuteaka-Philipsen BD, van der Heide A, Koper D, Keij-Deerenberg I, Rietjens JA, Rurup ML, Vrakking AM, Georges JJ, Muller MT, van der Wal G, van der Maas PJ.

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Empirical data on the rate of euthanasia, physician-assisted suicide, and other end-of-life decisions have greatly contributed to the debate about the role of such practices in modern health care. In the Netherlands, the continuing debate about whether and when physician-assisted dying is acceptable seems to be resulting in a gradual stabilisation of end-of-life practices. We replicated interview and death-certificate studies done in 1990 and 1995 to investigate whether end-of-life practices had altered between 1995 and 2001. Since 1995, the demand for physician-assisted death has not risen among patients and physicians, who seem to have become somewhat more reluctant in their attitude towards this practice.

PMID: 12907015 [PubMed - indexed for MEDLINE]

63: Lancet. 2003 Aug 2;362(9381):345-50.

End-of-life decision-making in six European countries: descriptive study.

van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E, van der Wal G, van der Maas PJ; EURELD consortium.

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BACKGROUND: Empirical data about end-of-life decision-making practices are scarce. We aimed to investigate frequency and characteristics of end-of-life decision-making practices in six European countries: Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland. **METHODS:** In all participating countries, deaths reported to death registries were stratified for cause (apart from in Switzerland), and samples were drawn from every stratum. Reporting doctors received a mailed questionnaire about the medical decision-making that had preceded the death of the patient. The data-collection procedure precluded identification of any of the doctors or patients. All deaths arose between June, 2001, and February, 2002. We weighted data to correct for stratification and to make results representative for all deaths: results were presented as weighted percentages. **FINDINGS:** The questionnaire response rate was 75% for the Netherlands, 67% for Switzerland, 62% for Denmark, 61% for Sweden, 59% for Belgium, and 44% for Italy. Total number of deaths studied was 20480. Death happened suddenly and unexpectedly in about a third of cases in all countries. The proportion of deaths that were preceded by any end-of-life decision ranged between 23% (Italy) and 51% (Switzerland). Administration of drugs with the explicit intention of hastening death varied between countries: about 1% or less in Denmark, Italy, Sweden, and Switzerland, 1.82% in Belgium, and 3.40% in the Netherlands. Large variations were recorded in the extent to which decisions were discussed with patients, relatives, and other caregivers. **INTERPRETATION:** Medical end-of-life decisions frequently precede dying in all participating countries. Patients and relatives are generally involved in decision-making in countries in which the frequency of making these decisions is high.

PMID: 12907005 [PubMed - indexed for MEDLINE]

64: Lancet. 2003 Aug 2;362(9381):408.

Comment on:

Lancet. 2003 May 10;361(9369):1603-7.

Spiritual wellbeing and care of terminally ill patients.

Steger B.

Publication Types:

Comment

Letter

PMID: 12907029 [PubMed - indexed for MEDLINE]

65: Lancet Neurol. 2003 Feb;2(2):76.

Artificial nutrition and hydration therapy in advanced dementia.

Gillick MR.

Department of Medicine, Hebrew Rehabilitation Center for Aged, 1200 Centre Street, Boston, MA 02131, USA. gillick@mail.hrca.harvard.edu
<gillick@mail.hrca.harvard.edu>

PMID: 12849261 [PubMed - indexed for MEDLINE]

66: Mayo Clin Proc. 2003 Aug;78(8):959-63.

Ethical analysis of withdrawal of pacemaker or implantable cardioverter-defibrillator support at the end of life.

Mueller PS, Hook CC, Hayes DL.

Division of General Internal Medicine, Mayo Clinic, Rochester, Minn 55905, USA.

OBJECTIVE: To describe a series of terminally ill patients who requested (or whose surrogates requested) withdrawal of pacemaker or implantable cardioverter-defibrillator (ICD) support and the ethical issues pertaining to these requests. PATIENTS AND METHODS: We performed a retrospective review of the medical records of patients seen at the Mayo Clinic in Rochester, Minn, between January 1996 and June 2002 and identified 6 terminally ill patients who requested (or whose family members requested) withdrawal of pacemaker or ICD support. Potential interventions were an ethics consultation and subsequent withdrawal of pacemaker or ICD support. The study's main outcome measures were death and the context in which it occurred. RESULTS: The mean age of the 6 patients (3 men, 3 women) was 75.5 years. Five had pacemakers, and 1 had an ICD. Five patients had advance directives that indicated a desire to withdraw medical interventions if death was inevitable. Two patients and 4 surrogates requested withdrawal of pacemaker or ICD support. One patient died without withdrawal of support despite an ethics consultation that endorsed its permissibility. Another died while an ethics consultation was in progress. The request to withdraw support was granted in 4 patients, all of whom died within 5 days of withdrawal of support. CONCLUSIONS: Granting terminally ill patients' requests to withdraw unwanted medical support is legal and ethical. Death after withdrawal of support is attributable to the patient's underlying pathology and is not the same as physician-assisted suicide or euthanasia. Clinician familiarity with these concepts may lead to more expeditious withdrawal of unwanted medical support from terminally ill patients.

PMID: 12911044 [PubMed - indexed for MEDLINE]

67: Med J Aust. 2003 Jul 7;179(1):57-8; author reply 60.

Comment on:

Med J Aust. 2003 Feb 17;178(4):171-4.

"Death talk": debating euthanasia and physician-assisted suicide in Australia.

Parker M.

Publication Types:

Comment

Letter

PMID: 12899179 [PubMed - indexed for MEDLINE]

68: Med J Aust. 2003 Jul 7;179(1):58-9; author reply 60.

Comment on:

Med J Aust. 2003 Feb 17;178(4):171-4.

"Death talk": debating euthanasia and physician-assisted suicide in Australia.

Anaf JM.

Publication Types:

Comment

Letter

PMID: 12899181 [PubMed - indexed for MEDLINE]

69: Med J Aust. 2003 Jul 7;179(1):59-60; author reply 60.

"Death talk": debating euthanasia and physician-assisted suicide in Australia.

Coombe FJ.

Publication Types:

Letter

PMID: 12899183 [PubMed - indexed for MEDLINE]

70: Med J Aust. 2003 Jul 7;179(1):57; author reply 60.

Comment on:

Med J Aust. 2003 Feb 17;178(4):171-4.

"Death talk": debating euthanasia and physician-assisted suicide in Australia.

Hunt RW.

Publication Types:

Comment
Letter

PMID: 12831391 [PubMed - indexed for MEDLINE]

71: Med Law. 2003;22(1):197-8.

Laws and practices relating to euthanasia and assisted suicide in 34 countries of the council of Europe and the USA.

[No authors listed]

PMID: 12809351 [PubMed - indexed for MEDLINE]

72: Natl Cathol Bioeth Q. 2001 Autumn;1(3):345-61.

Physician-assisted suicide: a current legal perspective.

Myers RS.

Ave Maria School of Law, Ann Arbor, Michigan, USA.

PMID: 12866524 [PubMed - indexed for MEDLINE]

73: Natl Cathol Bioeth Q. 2001 Autumn;1(3):363-94.

An inside look at the right-to-die movement.

Marker R.

International Task Force on Euthanasia and Assisted Suicide, Steubenville, Ohio, USA.

PMID: 12866525 [PubMed - indexed for MEDLINE]

74: Nurs Forum. 2003 Apr-Jun;38(2):25-8.

Palliative care: a discussion of management and ethical issues.

Chrystal-Frances E.

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Echrystal@aol.com

Publication Types:
Review
Review, Tutorial

PMID: 12894629 [PubMed - indexed for MEDLINE]

75: Nurs Older People. 2003 Jun;15(4):18-21.

Dementia and personhood: implications for advance directives.

Moody J.

Faculty of Health and Life Sciences, School of Acute and Continuing Care
Nursing, Napier University.

Publication Types:

Review

Review, Tutorial

PMID: 12808830 [PubMed - indexed for MEDLINE]

76: Nurs Res. 2003 Jul-Aug;52(4):217-25.

Determinants of hospice home care use among terminally ill cancer patients.

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BACKGROUND: Despite the widespread availability of hospice services for more than two decades in the United States, currently many terminally ill cancer patients who may benefit from hospice care do not receive it. **PURPOSE:** To identify determinants of the use of hospice home care services for terminally ill cancer patients during their final days of life. **METHODS:** Secondary analysis of data from 127 terminally ill cancer patients who participated in a prospective and exploratory study aimed at identifying determinants of congruence between the preferred and actual place of death. Multivariate logistic regression analysis was conducted to identify determinants of hospice home care use. **RESULTS:** Sixty-four (50.4%) out of the 127 participants had used hospice home care services before death. Important determinants of hospice home care use included: (a) longer length of survival (odds ratio [OR] 1.02; 95% confidence interval [CI]: 1.01-1.03); (b) perceived greater family ability to achieve preferred place of death (OR: 1.85; 95% CI: 1.30-2.62); (c) home as the realistic preferred place of death (OR: 5.58; 95% CI: 1.95-16.03); (d) being female (OR: 5.37; 95% CI: 1.81-15.95); (e) lower levels of functional dependency (OR: 0.94; 95% CI: 0.89-0.99); and (f) use of emergency care during the final days of life (OR: 4.03; 95% CI: 1.26-12.94). **CONCLUSIONS:** The results of this study identified several groups of terminally ill cancer patients who were at a disadvantage to use hospice home care, including those without sufficient family resources but who required intensive nursing care. Providing nursing care that enables family care-taking at home may facilitate hospice home care use for patients.

PMID: 12867778 [PubMed - indexed for MEDLINE]

77: Palliat Med. 2003 Jul;17(5):403-9.

Health professionals' views on advance directives: a qualitative interdisciplinary study.

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The aim of this study was to discover the views of health professionals in the Greater Glasgow area on advance directives, using semi-structured interviews and focus groups. The twelve participants interviewed included four hospital doctors, four general practitioners (GPs) and four nurses. The six focus groups comprised hospice nurses, GPs, consultant geriatricians, geriatricians in training grades and an interdisciplinary group. Participants were purposively selected to reflect a range of personal experiences with, and attitudes toward, the advance directive using key informants and a short questionnaire. Participants were asked to comment on a specially constructed sample advance directive. All research encounters were recorded, transcribed and analysed using accepted methods in qualitative research. The advance directive was seen as a means of promoting peace of mind in will makers, of allowing carers to honour the patients' wishes and of stimulating communication between all parties. Conversely the advance directive was seen as generating certain risks for the will maker--including those of coercion, misunderstanding, paradoxical overintervention and inadvertent undertreating. A core concern surrounded the issue of 'informedness' in will makers and the ethics of deciding for a future demented self.

PMID: 12882258 [PubMed - indexed for MEDLINE]

78: Palliat Med. 2003 Jul;17(5):395-402.

Use of hermeneutic research in understanding the meaning of desire for euthanasia.

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The philosophy of palliative care is holistic, paying attention to the multidimensional needs of the terminally ill in promoting quality of life and relieving suffering. These needs have to be viewed within their cultural, temporal and social contexts. Thus in conducting patient need-based research, the patients' perspectives are vital data in providing intimate insight into the core issues of any phenomenon under study. This paper aims to illustrate the usefulness of hermeneutic philosophy in palliative care research, as demonstrated in a study to understand the meaning of desire for euthanasia directly from the terminally ill. Two particular aspects of the study are

emphasized, namely the research methodology and research process, rather than its findings regarding the meaning of desire for euthanasia. Hermeneutic philosophy parallels that of palliative care, as it also values human experience and social contexts. This approach allows in-depth understanding into a phenomenon in a humane and holistic manner, with adherence to methodological and

scientific rigour. The process of hermeneutic interpretation can also promote evidence-based reflective practice. The adoption of a hermeneutic attitude in clinical practice can refine professional self-development in the art of communication and caring.

PMID: 12882257 [PubMed - indexed for MEDLINE]

79: Palliat Med. 2003 Jul;17(5):393-4.

Comment on:

Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

Palliative care and euthanasia in countries with a law on euthanasia.

Deliens L, Bernheim J.

Publication Types:

Comment

Letter

PMID: 12882255 [PubMed - indexed for MEDLINE]

80: Palliat Med. 2003 Jul;17(5):387-92.

Comment on:

Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

Palliative care on the 'slippery slope' towards euthanasia?

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Publication Types:

Comment

PMID: 12882253 [PubMed - indexed for MEDLINE]

81: Palliat Med. 2003 Jul;17(5):445-53.

Determinants of the place of death among terminally ill cancer patients under home hospice care in Japan.

Fukui S, Kawagoe H, Masako S, Noriko N, Hiroko N, Toshie M.

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Although the place of death of patients with terminal cancer is influenced by multiple factors, few studies have systematically investigated its determinants. The purpose of this study was to examine the influence of the patients' sociodemographic, clinical and support network variables on the place of death of terminally ill cancer patients under the care of home care agencies in Japan. Among 528 patients from 259 home care agencies, 342 (65%) died at home and 186 (35%) died at a hospital. From the multivariate logistic regression model, patients who expressed the desire for receiving home care at referral [odds ratio (OR), 95% confidence interval (CI): 2.19, 1.09-4.40] in addition to the family caregiver's desire for the same (OR, 95%CI: 3.19, 1.75-5.81), who had more than one family caregiver (OR, 95%CI: 2.28, 1.05-4.94), who had the support of their family physician (OR, 95%CI: 2.23, 1.21-4.08), who were never rehospitalized (OR, 95%CI: 0.04, 0.02-0.07), who received more home visits by the home hospice nurse during the stable phase under home hospice care (OR, 95%CI: 1.25, 1.02-1.53), and who were in the greatest functionally dependent status during the last week prior to death (OR, 95%CI: 8.60, 4.97-14.89) were more likely to die at home. Overall, this model could accurately classify 95% of the places of death, which is higher than other published studies. A clearer understanding of factors that might influence the place of death of terminally ill cancer patients would allow healthcare professionals to modify healthcare systems and tailor effective interventions to help patients die at their place of preference.

PMID: 12882263 [PubMed - indexed for MEDLINE]

82: Palliat Med. 2003 Jul;17(5):454-60.

The impact on the family of terminal restlessness and its management.

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The purpose of this qualitative study was to explore and describe the impact of terminal restlessness and its management upon family members who were witness to the event. Approximately 25%-85% of terminally ill patients may experience the symptoms associated with terminal restlessness during the hours or days before their death. They may be physically agitated and cognitively impaired and often appear to be suffering. Treatment of these severe symptoms usually involves the use of sedating medications that can affect these patients' ability to communicate with their families. Using a phenomenological research approach, two focus groups and 20 individual interviews were held with bereaved family members and hospice staff. A content analysis of the data resulted in the emergence of several core themes that reflected the participants' perceptions and experiences; the multidimensionality of suffering, the need for communication,

feelings of ambivalence, the need for information and sensitivity and respect. It is suggested that the development and implementation of a multiprofessional team protocol could address the specific concerns, information and care needs of these families at this critical time.

PMID: 12882264 [PubMed - indexed for MEDLINE]

83: Palliat Med. 2003 Jul;17(5):465-7.

The potential role for automatic external defibrillators in palliative care units.

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Cardiopulmonary resuscitation (CPR) has received frequent attention by professionals and the public in recent times. Concerns regarding the potential harms for little chance of success have caused palliative care units (PCUs) doubts about initiating CPR. However, there appears to be a moral responsibility to offer CPR to some, carefully selected, patients. Automatic external defibrillators (AEDs) have been shown to significantly increase chances of survival following CPR and are simple to use, even for non-professionals. It is argued that AEDs may increase the moral imperative on PCUs to offer CPR to certain patients and provide the basis for a necessary debate on where the border between appropriate active treatment and a disturbance to the aim of a peaceful death rests.

Publication Types:
Review
Review, Tutorial

PMID: 12882266 [PubMed - indexed for MEDLINE]

84: Palliat Med. 2003 Jul;17(5):469.

Terminal restlessness and sedation: a note of caution.

Heyse-Moore L.

Publication Types:
Letter

PMID: 12882267 [PubMed - indexed for MEDLINE]

85: Posit Aware. 2003 Jul-Aug;14(4):25-8.

The grief suite.

Stern B.

Publication Types:
Newspaper Article

PMID: 12951946 [PubMed - indexed for MEDLINE]

86: Postgrad Med. 2003 Aug;114(2):9-10.

Embracing life, accepting limits. A physician's position is unique when a loved one faces death.

Setness PA.

Publication Types:
Editorial

PMID: 12926173 [PubMed - indexed for MEDLINE]

87: Psychooncology. 2003 Sep;12(6):620-7.

Couples therapy at end of life.

Mohr DC, Moran PJ, Kohn C, Hart S, Armstrong K, Dias R, Bergsland E, Folkman S.

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This study reports on a preliminary uncontrolled study of a treatment for couples in which one partner is diagnosed with a terminal illness. In this study nine couples, in which one partner was diagnosed with a terminal illness and had less than 18 months to live, were offered eight sessions of couples therapy. Follow-up data were available for six couples. Two patients died during treatment and a third patient moved out of the area prior to completing the follow-up assessment. Significant decreases were seen in the patients' distress about dying and the frequency of partners' worry about their partner dying. Improvements were also seen in relationship quality. While the size of the study precludes generalizing these findings to a larger population, this study supports further exploration of couples therapy as a potentially useful adjunct to end of life care. Copyright 2003 John Wiley & Sons, Ltd.

PMID: 12923802 [PubMed - in process]

88: Radiology. 2003 Aug;228(2):309-12.

The end of life.

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PMID: 12893892 [PubMed - indexed for MEDLINE]

89: Soc Sci Med. 2003 Nov;57(9):1609-20.

Physicians' experiences of caring for late-stage HIV patients in the post-HAART era: challenges and adaptations.

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As medical treatment for AIDS has become more complex, the need for good palliative and end-of-life care has also increased for patients with advanced disease. Such care is often inadequate, especially among low-income, ethnic minority patients. The current study investigated physicians' experiences with caring for dying HIV patients in an underserved, inner city community in the Bronx, NY. The goals of the study included: (1) to investigate the barriers to effective end-of-life care for HIV patients; and (2) to examine physicians' experiences of role hindrance and frustration in caring for dying patients in the era of HAART. Qualitative, open-ended interviews were conducted with 16 physicians. Physicians identified two core, prescriptive myths shaping their care for patients with HIV. The 'Good Doctor Myth' equates good medical care with the delivery of efficacious biomedical care. The role of the physician is defined as technical curer, while the patient's role is limited to consultation and compliance. The 'Good Death Myth' envisions an ideal death which is acknowledged, organized, and pain free: the role of the physician is defined as that of comforter and supporter in the dying process. Role expectations associated with these myths were often disappointed. First, late-stage patients refused to adhere to treatment and were thus dying "unnecessarily." Second, patients often refused to acknowledge, accept, or plan for the end of life and as a result died painful, chaotic deaths. These realities presented intense psychological and practical challenges for providers. Adaptive coping included both behavioral and cognitive strategies. Successful adaptation resulted in "positive engagement," experienced by participants as a continuing sense of fascination, gratification, and joy. Less successful adaptation could result in detachment or anger. Participants believed that engagement had a powerful impact on patient care. Working with dying HIV patients in the post-HAART era of efficacious treatment challenges physician's cherished roles and values. Physicians adapt to the challenge through a variety of cognitive and behavioral strategies. The failure to adapt successfully has psychological consequences for providers that may impact patient care.

PMID: 12948570 [PubMed - in process]

90: Soc Sci Med. 2003 Oct;57(8):1375-85.

Disarmed complaints: unpacking satisfaction with end-of-life care.

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Difficult health care encounters often do not translate into expressions of dissatisfaction with care. This paper focuses on the 'non-expression' of dissatisfaction with care in the accounts of 12 people in Canada who provided care to a relative or friend who died of breast cancer. The analysis foregrounded in this paper began from the observation that as difficult health care experiences were elaborated, speakers located health professionals' actions in relation to various situational factors, including the fact of a (cancer) death and conditions of constraint in the health system. Set alongside these two realities, expressions of dissatisfaction tended to be disarmed. Results of this study suggest that the cost of articulating dissatisfaction with care is high where the cared-for person has died, and the perceived value of focusing on difficult experiences is low. Further, respondents in this study took the specificity of the situation and the setting into account in formulating beliefs about the care outcomes for which health professionals could be held responsible. When conditions in the health system and the disease process of advanced cancer were positioned in talk as 'ultimate limits' on health professionals' actions, perceived lapses in care were excused.

PMID: 12927468 [PubMed - in process]

91: Soc Sci Med. 2003 Aug;57(4):721-31.

Physician and family assisted suicide: results from a study of public attitudes in Britain.

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Legalisation of assisted suicide presents a dilemma for society. This arises because of a lack of consensus regarding the precedence to be accorded freedom of choice versus the inviolability of human life. Several factors including improvements in medical technology, population ageing and changing perceptions about quality of life serve to make a re-examination of attitudes to this issue appropriate at this time. Within this context, data from the 1983, 1984, 1989 and 1994 British Social Attitudes Surveys (BSAS) were examined. These demonstrate a slight increase in support for physician-assisted suicide (PAS) from around 75% to around 84% over the 11-year period in Britain. A much lower level of support (54%) was recorded in relation to family-assisted suicide (FAS). A logistic regression analysis of data from the 1994 survey was undertaken to establish the relationship between attitudes toward legalisation of PAS and FAS and the characteristics of the respondent. Strength of religious affiliation was found to be a significant determinant of opposition to legalisation of both. Religious denomination was found to be marginally significant in relation to PAS but not FAS. Members of the Church of England,

non-Christian faiths and those of no faith were found to be marginally more likely to support legalisation of PAS, than Roman Catholics or those of other Christian faiths. Education, income, sex, marital status, long-standing illness and age were not found to be significant predictors of attitude. In relation to FAS age was also found to be significant predictor of opposition. Findings here suggest that if Britain continues to become a more secularised society, support for legalisation of PAS (and FAS) is likely to increase. As health care costs continue to grow and the ability to extend life (even where the quality of that life may be poor) increases, pressure for legalisation of PAS may increase.

PMID: 12821019 [PubMed - indexed for MEDLINE]

92: South Med J. 2003 Apr;96(4):391-3.

End-of-life issues and spiritual histories.

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BACKGROUND: Patients facing end-of-life issues have spiritual concerns that may have an impact on their medical decision-making. METHODS: To determine whether physicians address spiritual concerns in this context, we reviewed the charts of 92 elderly hospitalized patients facing decisions regarding resuscitation status or feeding tube placement. RESULTS: The average age of the participants was 72.4 years and 51% of them were female. Only 6.5% of the patients had spiritual histories documented in their charts; 29% had either a spiritual history or some mention of chaplain or psychiatrist involvement. CONCLUSION: Spiritual concerns of many patients facing end-of-life decisions are not being addressed.

PMID: 12916559 [PubMed - indexed for MEDLINE]

93: Support Care Cancer. 2003 May;11(5):294-303. Epub 2003 Mar 22.

Quality of life for oncology patients during the terminal period. Validation of the HRCA-QL index.

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AIM: The evolution of performance status, disability, and quality of life (QL) according to the Hebrew Rehabilitation Center for Aged QL (HRCA-QL) index for cancer patients through their terminal period is described. The assessment of HRCA-QL validity and reliability is also described. DESIGN: A total of 200 cancer patients were followed up from the onset of their "terminal phase" until they died. Information on symptoms, performance, disability and QL were collected by patient's oncologists in hospital and by their family practitioners

and community nurses when the patient was at home. Health measures were: the HRCA-QL index, Karnofsky performance status (KPS) and the Independence in Activities of Daily Living (IADL) index. RESULTS: The three indices were acceptable for a fair number of patients at the start of the terminal phase. Almost two-thirds had a KPS ≥ 60 . With respect to the IADL index, the patients were independent in five of the six functions, with 80% having a HRCA-QL equal to or greater than 4. The median duration of the terminal period was 59 days. All three indices declined progressively, with marked deterioration in the last 2 weeks. The HRCA-QL index was highly correlated with KPS and the IADL index, had good internal consistency and showed an acceptable test-retest and inter-rater reliability. The HRCA-QL index was reactive to clinical changes. CONCLUSIONS: All three scales confirmed that terminal patients experience a progressive loss of performance, increase in dependence and deterioration of QL as they approach the end of life. Based in these results, we consider the HTCA-QL index valid for use in terminal cancer patients.

Publication Types:
Validation Studies

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